

White House Conference on Aging Post-Event Summary Report

Name of Event: Ethics and Aging in Long-Term Care

Date of Event: May 19, 2005

Location of Event: The Jewish Home & Hospital Lifecare System
Sarah Neuman Center for Healthcare and Rehabilitation/Westchester Division

Number of Persons Attending: 200

Sponsoring Organizations: The Jewish Home & Hospital Lifecare System

Priority Issue #1:

- ◆ Issue(s): Legal regulation of nursing facilities may exert both positive and negative effects on the quality of care provided to nursing home residents. Public policy makers should establish a process for carefully evaluating these effects and devising strategies to maximize the law's positive, therapeutic impact on resident care.
- ◆ Barrier(s): Current public policy
- ◆ Proposed Solution(s): These strategies may include:
 - Professional education about real versus perceived legal risks and how they can be put into reasonable perspective by nursing facility providers
 - Encouraging nursing facility providers to make better use of legal and risk management advice
 - Enabling better communication among service providers
 - Facilitating better communication and negotiation between nursing facility providers, on one hand, and consumers and their families, on the other
 - Identification of reasonable treatment alternatives, guided by the Least Intrusive/Least Restrictive Alternative principle
 - Consultation and collaboration with Ethics Committees and other non-judicial means of resolving actual and potential problems
 - Promoting forms of documenting resident care that contribute to the quality of that care
 - Identifying and publicizing Best Practices
 - Developing and disseminating practice guidelines
 - Helping nursing facilities to develop and implement effective organizational policies and procedures
 - Considering and adopting legal reforms aimed at enhancing the law's therapeutic impact of its intended beneficiaries

Priority Issue #2:

- ◆ Issue(s): Informed Consent to Treatment (and Tx refusal)
- ◆ Barrier(s):
 - Lack of understanding about decision making levels of risk

- Lack of a policy and guidelines for determination of decision-making capacity
- Miscommunication
- Failure to recognize – and work with – family/cultural decision-making pattern/style
- Surrogate decision making is poorly effectuated or representative of patient's interests
- ◆ Proposed Solution(s):
 - Re-examine the Informed Consent model as a useful guidelines for this purpose.
 - Use a benefit-burden discussion model
 - Learn about other models of decision-making
 - Cultural sensitivity education
 - Examine the research!
 - Surrogate decision-maker training/education

Priority Issue #3:

- ◆ Issue(s): Culture Change: the link between empowerment (a key tenet of culture change and principle of autonomy) and improved clinical outcomes has not been scientifically demonstrated
- ◆ Barrier(s):
 - Failure to explore values and preferences with regard to quality of life
 - Absence of a coherent model of quality of life
 - Lack of a theoretical model of causation or association with inputs and desired outcomes
 - Insufficient clinical expertise regarding care of the older adult
 - Inadequate discussion of risk acceptance and meaning for resident, family, facility
 - Failure to explore and understand nature of dependency and caregiving
- ◆ Proposed Solution(s):
 - Develop coherent, relevant job descriptions.
 - Decide in advance how culture change will be known when it is achieved.
 - Measurable goals; replicable methods
 - Identify/describe accountability and methods by which it will exercised
 - Measure if residents are making meaningful (for them!) decisions

Priority Issue #4:

- ◆ Issue(s): Communicating/Informing: quintessential ethical engagement
- ◆ Barrier(s):
 - Unawareness of information needs how information is to be transmitted
 - Failure to determine what patient/family understands
 - Insensitivity to reluctance to ask questions (loss of face, etc.)
 - Not knowing how to deliver bad news

◆ Proposed Solution(s):

- Determine in advance who the stakeholders are in the communication: who (ie, what are the role requirements?), what will be communicated (level of detail), when (timing, frequency), how/by what means, where
- Determine understanding by asking “Tell me in your own words what I just said” rather than by asking “Any questions?”
- Learn in advance what patient/family wants to know
- Have all the medical facts available

Priority Issue #5:

◆ Issue(s): Placebo Medication/Treatment

◆ Barrier(s):

- Unwillingness/resistance to recognition of placebo effect
- Ethical principle that “forbids” deception
- Loss of faith in provider if deception discovered
- Principle of truth telling is violated; harm is caused
- Competing ethical theories: consequentialism vs. deontology – or, consequences vs. rules
- Research studies inconclusive but appear to find a placebo effect

◆ Proposed Solution(s):

- Consider validity of justice principle (ie, resources) as rationale for placebo administration
- Appropriate language can maintain the trusting relationship while still permitting placebo administration: This pill *may* help your pain vs. This pill *will* help your pain
- Continue research, particularly with regard to expectancy theory